



**FOR IMMEDIATE RELEASE:**  
November 2, 2022

**MEDIA CONTACT:**  
Jennifer Rate  
Marketing & Communications Manager  
[jrate@aakp.org](mailto:jrate@aakp.org)  
(813) 400-2394

## **KIDNEY ADVOCATES RECEIVE U.S. PRESIDENT'S ACHIEVEMENT AWARD**

**Washington, DC:** The American Association of Kidney Patients (AAKP), the nation's largest independent kidney patient organization, today announced the names of patients and advocates who have been specially recognized by President Joseph R. Biden with U.S. Presidential Volunteer Service Awards (PVSA's). The highly competitive and non-partisan national award recognizes the exceptional contributions of AAKP volunteers to both the organization and the wider kidney community. AAKP is a driver behind greater national and global patient care choice and access to new therapies to delay disease progression, stop kidney failure, and increase kidney transplantation, including pre-emptive transplants, wider utilization of home dialysis, and the rapid development of safe, artificial implantable and wearable organs.

Six AAKP leaders received the President's Lifetime Achievement Award, the highest level of recognition that is unique and recognizes an exemplary level of volunteerism to build a stronger nation through volunteer service, including the investment of thousands of hours of personal time and professional expertise. The AAKP members who received the Presidential Lifetime Achievement Award, as well as PVSA awards at the gold, silver, and bronze levels, are nationally known advocates deeply involved in efforts to impact kidney science, innovation, and policy through collaborations with top kidney scientists, elected and appointed leaders, federal agencies, investors, major companies and startups, and nearly every major academic research center and university involved in kidney research ([read more](#)). AAKP provides expert advice to over 200 national and international companies, non-governmental organizations, and U.S. federal government agencies on issues ranging from patient-centered policies, quality metrics, regulatory and payment issues, and how to collaborate more effectively with patients and incorporate their unique insights and lived experiences.

Diana Clynes, AAKP Executive Director, stated, "AAKP has expanded tremendously over the past decade and has accelerated our impact on kidney policy, research, and innovation due to the expertise and selfless service of our patient consumer volunteers. We operate on a national strategy, crafted by patients and not consultants, anchored on the core principle of patient consumer care choice. There is no greater driving force for kidney health and care innovation or greater ally to those working to transcend high-mortality status quo care than the organized and independent voices of patients who have managed kidney disease. The AAKP professional team is honored and privileged to work with these patient leaders, and we are intensely proud of the recognition of their impact by President Biden."

AAKP is a PVSA-authorized and certifying organization and the largest organization in the kidney space that participates in this important American initiative. In 2020, AAKP launched its inaugural PVSA program, and twenty-nine kidney advocates received recognition from President Donald J. Trump for their work to educate high-risk immunosuppressed and immunocompromised kidney patients on threats posed by COVID-19. The PVSA was founded by President George W. Bush in the aftermath of the terror attacks of September 11, 2001, as one of several initiatives, including the President's Council on Service and Civic Participation, designed to encourage and exemplify the strength of outstanding American volunteerism and community engagement. The award program has continued under successive presidential administrations. The PVSA program is led by [AmeriCorps](#) (formerly the Corporation for National and Community Service), an organization whose vision originated in the administration of

President William J. Clinton, and is managed in partnership with [Points of Light](#), an organization whose vision is rooted in the administration of President George H.W. Bush.

In 2019, in coordination with the launch of the White House *Executive Order on Advancing American Kidney Health*, AAKP launched [The Decade of the Kidney™](#) to build national and international networks that prioritize kidney health as both a healthcare and workforce issue and to facilitate greater investments in research and broader private sector involvement in care innovations. Through AAKP's Center for Patient Engagement and Advocacy and Center for Patient Research and Education, the Association has dramatically expanded its patient databases, social media recruitment, and analytics tools. AAKP volunteers engage in dozens of requests every year for clinical trial awareness and recruitment campaigns, patient advisory boards, technical evaluation panels, focus groups, patient surveys, clinical research, and public policy research. AAKP also offers [online training](#) for patients on how to be equally effective collaborators.

In 2022, AAKP volunteers and advocates continued to expand the organization's national and global impact through a growing [Patient Ambassador Initiative](#), the expansion of AAKP's non-partisan [KidneyVoter™](#) voter registration campaign, and the launch of AAKP's [Patient Voice Patient Choice™](#) initiative to increase patient access to new drugs and devices. AAKP patients and advocates use sophisticated virtual platforms, international patient group partnerships, clinical journal editorials, television, radio, and social media to advance the Association's mission to educate the public on the devastating impacts of kidney diseases. For 2022, the organization conducted multiple national and international events that engaged over 180 national and international medical and patient experts and expanded the international audience of its [Global Summit on Kidney Disease Innovations](#) to over 90 countries.

At the federal level, AAKP volunteers receiving PVSAs have impacted research and development initiatives across the Departments of Health and Human Services (HHS), the Department of Veterans Affairs (VA), and the Department of Defense (DOD) via the Congressionally Directed Medical Research Program (CDMRP) and other DOD activities. Further, AAKP has been actively involved in patient engagement initiatives and the development of patient insight data alongside the U.S. Food and Drug Administration (FDA), the Centers for Medicare and Medicaid Services (CMS), the Centers for Disease Control and Prevention (CDC), the Health Resources and Services Administration (HRSA), and multiple other federal agencies.

Status quo kidney care, especially care administered in dialysis centers, is based on outdated medical technologies and professional practices, results in disability and unemployment, and is associated with extremely high mortality. AAKP, along with other kidney organizations dedicated to disrupting and transforming status quo care, supports patient consumer access to new therapies and efforts to diagnose the disease further upstream. Earlier detection and treatment of kidney diseases improves health outcomes, decreases patient burdens and impacts on the health care system, and limits costs to taxpayers.

### **Presidential Volunteer Service Award Honorees**

#### **President's Lifetime Achievement Award:**

- [Richard Knight \(MD\)](#), former dialysis patient, 16-year transplant recipient; AAKP President; Member, National Institutes of Health/NIDDK Strategic Planning Committee; Co-Chair, Community Engagement Committee, NIH/NIDDK Kidney Precision Medicine Project; Member, Scientific Registry of Transplant Recipients (SRTR) Visiting Committee; 2017 recipient, American Society of Nephrology's President's Medal; 2020 PVSA recipient
- [Edward V. Hickey III \(CA\)](#), USMC veteran, kidney patient; AAKP Vice President; Chair of AAKP Veterans Health Initiative (VHI); Reviewer, Department of Defense Congressionally Directed Medical Research Program; AAKP liaison, U.S. Department of Veterans Affairs; Member, Judging Panel, U.S. Department of Health and Human Services/American Society of Nephrology KidneyX COVID-19 Kidney Care Challenge; 2020 PVSA recipient
- [Paul T. Conway \(VA\)](#), former dialysis patient, 25-year transplant recipient; AAKP Chair of Public Policy and Global Affairs; Co-Chair, AAKP/George Washington University Global Summit on

- Kidney Disease Innovations; Member, American Board of Internal Medicine's Nephrology Specialty Board; Chair, FDA Patient Engagement Advisory Committee; Member, Observational Study Monitoring Board, National Institutes of Health/NIDDK Kidney Precision Medicine Project; 2017 recipient, American Society of Nephrology's President's Medal; 2020 PVSA recipient
- **Suzanne Ruff (NC)**, living organ donor; author, *The Reluctant Donor*; freelance writer, Charlotte Observer; AAKP National Board of Director and National Ambassador; 2020 PVSA recipient
  - **Dr. Stephen Fadem (TX)**, patient, Clinical Professor of Medicine, Baylor College of Medicine, Section of Nephrology; Chair, AAKP Medical Advisory Board; AAKP Life Member; Recipient, AAKP's Samuel J. Orenstein and Peter Lundin, MD Awards; AAKP Historian; recipient of AAKP Lifetime Achievement Award; 2020 PVSA recipient
  - **Bob Abbott (AR)**, caregiver; Charter Member, Arkansas Kidney Disease Commission; AAKP Life Member; recipient, AAKP Samuel J. Orenstein Award (2011); recipient, 2019 AAKP National Patient Engagement and Advocacy Award; 2020 PVSA recipient

#### **PVSA Gold Medal:**

- **Kent Bressler, MA, RN (TX)**, U.S. Army veteran, pre-emptive transplant recipient; AAKP National Board of Director and National Ambassador; Reviewer, Department of Defense CDMRP; Co-founder of Kidney Solutions; and host of Kent's Kidney Stories Podcast series; 2020 PVSA recipient
- **Jennifer Jones (VA)**, USMC veteran, former dialysis patient, current transplant recipient; AAKP National Board of Director and National Ambassador; 2019 recipient of AAKP National Social Media Education and Advocacy Award; 2020 PVSA recipient
- **Dr. Janice Lea (GA)**, Professor of Medicine, Emory University; CMO, Emory Dialysis; AAKP National Board of Director; 2019 recipient, AAKP Samuel J. Orenstein Award; Principal Investigator, AAKP PCORI Engagement Awards; 2020 PVSA recipient
- **Dr. Dominic Raj (VA)**, Professor and Director, the Division of Kidney Diseases and Hypertension, George Washington University School of Medicine and Health Sciences; Co-chair, AAKP/GWU Global Summit on Kidney Innovations; 2019 recipient, AAKP Peter Lundin, MD Award; 2020 PVSA recipient
- **Glenda Roberts (WA)**, former dialysis patient; current transplant recipient; Director, External Relations and Patient Engagement, the Kidney Research Institute (KRI); AAKP National Ambassador; Member, Patient Advisory Board for Center for Dialysis Innovation; former Executive Director, Transplant House; 2020 PVSA recipient
- **David Rodriguez (TX)**, former dialysis patient, current transplant recipient; Patient Specialist, University Transplant Center San Antonio; AAKP National Board of Director and National Ambassador; member, AAKP Public Policy Committee; 2020 PVSA recipient
- **Dale Rogers (ID)**, former dialysis patient, current transplant recipient; AAKP National Board of Director and National Ambassador; member of AAKP Programs/Development Committee; AAKP Peer Mentor; 2020 PVSA recipient
- **Dr. Barry Smith (NY)**, Founder, Dreyfus Health Policy and Research Center; former President/CEO, The Rogosin Institute; AAKP National Board of Director; 2020 PVSA recipient
- **Dr. Jonathan Himmelfarb (WA)**, Co-Director, the University of Washington Center for Dialysis Innovation; Director, the Kidney Research Institute; Professor of Medicine and Adjunct Professor of Bioengineering; expert presenter, AAKP Global Summit on Kidney Disease Innovation and AAKP National Patient Meeting
- **Dr. William Fissell (TN)**, Medical Director, The Kidney Project; Associate Professor of Clinical Medicine, Vanderbilt University Medical Center; AAKP Medal of Excellence Award recipient; expert presenter, AAKP Global Summit on Kidney Disease Innovation, AAKP National Patient Meeting, and AAKP Policy Summit; profile feature, AAKP Innovator series
- **Dr. Shuvo Roy (CA)**, Technical Director, The Kidney Project; Professor, Departments of Bioengineering and Therapeutics Sciences and Surgery; 2021 KidneyX Artificial Kidney Prize Winner; AAKP Medal of Excellence Award recipient; expert presenter, AAKP Global Summit on Kidney Disease Innovation, AAKP National Patient Meeting, and AAKP Policy Summit

#### **PVSA Silver Medal:**

- **Melissa Bensouda (TX)**, former transplant recipient, current home hemodialysis patient; AAKP National Ambassador; 2020 PVSA recipient

- **Dr. Muralidharan Jagadeesan (DC)**, Associate Professor of Medicine, the Division of Renal Diseases and Hypertension and Chairman of Transplant Medicine; Medical Director, Kidney-Pancreas Transplant Program at the George Washington School of Medicine and Health Sciences; Faculty and Planning Committee Member, AAKP/GWU Global Summit on Kidney Innovations; 2020 PVSA recipient
- **Katina Lang-Lindsey, PhD, LMSW (AL)**, former dialysis patient, current transplant recipient; Assistant Professor, A&M University; AAKP National Ambassador; 2020 recipient, AAKP Patient Safety Award; 2020 PVSA recipient
- **Dammeon Marshall, MSW (GA)**, MSW; kidney disease patient; self-employed/entrepreneur; AAKP National Ambassador; 2020 PVSA recipient
- **James Myers (IN)**, former dialysis patient, current transplant recipient; AAKP National Board of Director and National Ambassador; Chair, AAKP Strategic Communications Committee; Chair, AAKP Pediatric Kidney Pals Initiative; 2015 recipient, Inaugural AAKP National Social Media Education and Advocacy Award; 2020 PVSA recipient
- **Sharron Rouse (MD)**, former dialysis patient, current transplant recipient; AAKP National Ambassador; Founder, Kindness for Kidneys International; 2020 recipient, AAKP Support Group of the Year Award; Co-Chair, 2020 AAKP National Patient Meeting; AAKP Peer Mentor; 2020 PVSA recipient
- **Lana Schmidt, MBA (IL)**, former home hemodialysis patient, current transplant recipient; AAKP National Board of Director and National Ambassador; Member, AAKP Strategic Communications Committee; 2020 PVSA recipient

#### **PVSA Bronze Medal:**

- **Catherine Campbell, DNP, RN, MBA, CHC, CCM, FACHE (TX)**, pre-emptive transplant recipient; AAKP National Board of Director and National Ambassador; Member, the Patient Engagement and Return of Results Committee and Community Advisory Board Committee for the National Institutes of Health Kidney Precision Medicine Project; Working Group Member, International T Cell-Mediated Rejection Project
- **Sara Eve Schaeffer, MBA, MA, RD (FL)**, AAKP National Board of Director; VP, Strategic Operations, Healthmap Solutions; former Executive Director, the Centers for Medicare and Medicaid Services' kidney contracts for Health Services Advisory Group
- **Shameka Ausborn (FL)**, former transplant recipient, current home hemodialysis patient; AAKP National Ambassador; AAKP Peer Mentor
- **Gitthaline "Candie" Gagne (PA)**, former dialysis patient, current transplant recipient; AAKP National Ambassador; Retired Navy Hospital Corpsman; Certified Surgical Technologist
- **Christine Hernandez, RN, BSN (IL)**, registered nurse, current in-center hemodialysis patient; AAKP National Ambassador
- **Terry Litchfield (WI)**, former caregiver to husband who was a long-term dialysis patient; AAKP National Ambassador
- **Roberta "Bobbie" Reed (PA)**, caregiver to son who is a transplant recipient; AAKP National Ambassador
- **Cecilia Santana (NY)**, former dialysis patient, current transplant recipient; AAKP National Ambassador; AAKP Peer Mentor; Wellness Ambassador, The Rogosin Institute
- **Mihi Wickramasinghe (CA)**, former transplant recipient, current peritoneal dialysis patient; AAKP National Ambassador
- **Leigh-Ann Williams (LA)**, current home hemodialysis patient; AAKP National Ambassador

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**About the American Association of Kidney Patients (AAKP):** Since 1969, AAKP has been the premier patient-led organization driving policy discussions on kidney patient consumer care choice and treatment innovation. Over the past decade, AAKP patients have helped gain lifetime transplant drug coverage for kidney transplant recipients (2020); new patient-centered policies via the White House Executive Order on Advancing American Kidney Health (2019); new job protections for living organ donors from the U.S. Department of Labor (2018); and Congressional legislation allowing HIV-positive organ transplants for HIV-positive patients (2013). Follow AAKP on social media at [@kidneypatient](#) on Facebook, [@kidneypatients](#) on Twitter, and [@kidneypatients](#) on Instagram, and visit [www.aakp.org](http://www.aakp.org) for more information.